

# CALIFORNIA

## One more weapon in war on cystic fibrosis

### Bill would add disease to screening program for infants

- [Dave Murphy, Chronicle Staff Writer](#)

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Kristi Dobson thought maybe she was being an overprotective, first-time mother when she kept taking daughter Amanda to doctors because of respiratory problems.

But when the Menlo Park woman's second daughter, Kelcey, had the same symptoms years later -- only worse -- doctors finally figured out what was wrong: Both children have cystic fibrosis, a genetic disease that hampers breathing, restricts nutrition and shortens lives.

Treatment slows its impact. A quarter of a century ago, children with CF weren't expected to see their 10th birthdays. Now they typically live into their mid-30s. And many states are following the federal Centers for Disease Control and Prevention's suggestion to routinely screen newborns for the disease.

But not California.

The state routinely tests the blood of newborns for dozens of diseases, but CF was left off the list when California greatly expanded its screening in 2004. The state wanted to do a pilot program first to make sure the CF test worked, which it did. So the state Senate Health Committee will consider a bill Wednesday that would add CF to the screening program, at an estimated cost of \$4.1 million.

"We already are providing these blood spots for children at birth," said state Sen. Liz Figueroa, the Fremont Democrat sponsoring the bill. "Including one more doesn't really mean anything" financially, she said, adding that the state would more than recover the \$4.1 million in reduced medical costs over the children's lifetimes.

Her bill already is garnering support from a variety of groups, including the March of Dimes and Lucile Packard Children's Hospital at Stanford -- Figueroa said she drafted the legislation at the request of a doctor from Packard. Although she expects some legislators to raise questions about the cost of the test -- which works out to about \$8 for each of California's 560,000 newborns -- she has not heard of any major opposition.

About 100 of the children tested each year will be found to have CF, said Sherri Sager, Packard's chief government relations officer. She said a study in Washington state estimated that millions of dollars are saved by doing the test.

"The longer the delay, you increase the health care cost and decrease the quality of life," Sager said.

Dobson said the uncertainty was particularly difficult when Kelcey was a sick infant, and medical people couldn't figure out why she wasn't growing the way she should. "They're looking at me like I'm not feeding my child."

Besides causing trouble to the lungs by producing thick mucus, CF also makes it hard for children to get proper nutrition, said Dr. Richard Moss, a pediatric pulmonologist at Packard.

"Part of CF affects the pancreas," Moss said. "One of the things the pancreas does is to help absorb food."

The pancreas also produces insulin, which regulates blood sugar. That's why at least one-fourth of CF patients end up with diabetes.

"The diabetes tends to come later in life," Moss said. "For most CF patients, it comes as teenagers or even adults."

So the earlier patients are diagnosed, the more nutritional help they can receive, such as with vitamins and supplemental enzymes. And good nutrition usually leads to longer lives.

"Screening should add a giant step forward," Moss said.

Although CF is genetic -- the second most common such disease in the United States, behind sickle cell, that hits children and shortens lives -- simply testing parents isn't conclusive. Although both parents must have the defective gene for a child to be born with CF, only about 1 in 4 of their children ends up with CF.

Although fewer than 30,000 Americans have CF, about 10 million carry the defective gene, according to Cystic Fibrosis Research in Mountain View.

Moss said more obstetricians are testing for CF during pregnancy, but only if there is a family history of the disease. Although Dobson and husband Paul obviously carry the gene, she said neither knew of any family members with it.

Even among their children, results were different. Although 12-year-old Amanda and 6-year-old Kelcey both have CF, 9-year-old son Maxwell does not.

Once the diagnosis came in four years ago, the parents made some big decisions. The girls received more aggressive medical treatments, of course, and there was more emphasis on sports and activities that would keep the lungs healthy. In 2003, they decided to leave the Portland area and move to Menlo Park, partly because they had family here -- Paul Dobson grew up in Redwood City -- but mostly because of Packard's strong reputation.

Mom's a little scared to have a trampoline in the backyard, but there it is, because fitness trumps parental caution. When other children are sick, Amanda and Kelcey are kept away, because sometimes their colds can last for months. But the caution is limited.

"Do I walk around with a can of Lysol?" Kristi Dobson says. "No."

Amanda does gymnastics, and her group is going to China in July. Kristi said one positive aspect of having CF in the family is that they embrace life more, which means Mom, Dad and daughter will make the China trip together.

As for Amanda, she tries to keep a low profile about the disease. One month short of being a teenager, she sure as heck isn't telling classmates or teachers about having CF. Her symptoms are still generally light enough that she can get away with it.

"You see a child who has MS or cerebral palsy, and you automatically see they have a disease," Kristi Dobson said. "With kids with CF, people just automatically assume, 'Oh, they're just not that sick.' "

What people don't see is how many medications they have to take -- Kelcey takes at least 11, twice a day -- or how they usually have to put on a vibrating vest twice a day and get aerosol pumped into them, trying to keep their lungs free of congestion.

When asked if there is any treatment that's a particular nuisance, Amanda's answer is simple. "All of them."

As for Mom, she is busy helping her daughters and working with Packard to better educate parents about the disease and treatment.

"I think early detection is key," she said. "At least you have something you can fight."

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